First FAMILY Stakeholder Dialogue Event

Post-event report

The 1st FAMILY Stakeholder Dialogue Event took place on January 17th, 2024 and 42 participants from across Europe attended the online event. The main objective was to collect the views of mental healthcare professionals on the ethical aspects and social consequences of prediction of risk of severe mental illness. Risk prediction for mental health problems is a prominent focus of research in psychiatry. However, risk prediction comes with ethical and social challenges, such as questions about informed consent, the right not to know, risk of stigmatisation and discrimination, empowerment and strengthening resilience of affected families, responsible use of Artificial Intelligence etc.

One of the envisaged outcomes of the FAMILY project is the development of ethical guidelines on the prediction of risk of severe mental illness for health care professionals involved in care of affected families. Mapping and evaluation of attitudes and opinions of health care professionals are critical for successful development of these guidelines. By gathering the views, needs and potential involvement of healthcare professionals regarding risk prediction in clinical care, we collected input for the planned FAMILY survey on the same topic for healthcare professionals across Europe. To facilitate the discussion, two fictional case scenarios were provided which were discussed in break out groups

Background
In recent years, researchers focus on developing ways to predict which children or adolescents will suffer from mental health problems later in life, in an attempt to offer preventative interventions to postpone or prevent onset and strengthen resilience during a time of high brain plasticity. In particular, in families where one or both parents suffer from mental health problems, the risk for their offspring to develop such problems is relatively high. Imagine that there is a novel prediction tool available for use in clinical practice, which allows to communicate with parents and their offspring the risk of severe mental illness later in life in the offspring. Such a tool will use artificial intelligence (AI). It will be based on the analyses of large amounts of individual and family information acquired through questionnaires, tests and interviews and may also include biological measures (e.g. genetic information, neuroimaging), considering both risk and resilience factors. The tool is validated in independent samples and is officially approved for use in clinical practice. We here assume that the tool can make predictions at a relatively early age, well before disease manifestation.
Scenario 1
Anna and Derek are parents to two sons, aged 3 and 5. In Anna's family history, some close relatives have experienced schizophrenia. The couple is currently contemplating enrolling their eldest son in sports lessons, considering options like sports dancing and gymnastics. These activities involve rigorous training and regular competitions, which would become a significant part of the child's life. Concerned about the potential stress and its impact on their son's mental health in the long run, Anna has discussed her family's medical history with the family doctor and child psychiatrist and has expressed her worry about the potential negative effects of professional sports on the child's mental well-being. Derek, on the other hand, holds the belief that engaging in sports is crucial for the holistic development of children. Despite the concerns raised by Anna, he emphasizes the importance of sports in fostering physical fitness, discipline, and valuable life skills. The couple is navigating the decision-making process, considering both the potential benefits and risks associated with introducing their eldest son to organized sports at a young age.

Scenario 2

Johann has been diagnosed with schizophrenia when he was 20 years old, and also some of his close relatives have experienced schizophrenia. Now Johann is 55, he has been married for a long time and has three children. During his discussions with his psychiatrist, he opens up about the challenges his family faces. Johann's eldest son David has become a successful businessman and is father to two children. Johann's daughter Emma excels in her studies and currently shows no signs of mental illness. Although she aspires to have children in the future, there is a lingering fear that they might inherit her father's condition. Johann's youngest child Dorothea, who is 13, is navigating the turbulent waters of adolescence. As a rebellious teenager, she occasionally exhibits emotional behaviour, struggles with sleep issues, and dabbles in experimentation with alcohol. Johann expresses deep concern about Dorathea's behaviour and mental well-being, highlighting the need for support and guidance especially in the context of the complexities of his family's mental health dynamics.

Results of the group discussions

During the discussion, four main themes were raised by the participants: (1) need for new professional knowledge and skills, (2) benefits and risks, (3) actionability, and (4) conditions for use. These main themes were further expanded and detailed as shown in Figure 1.

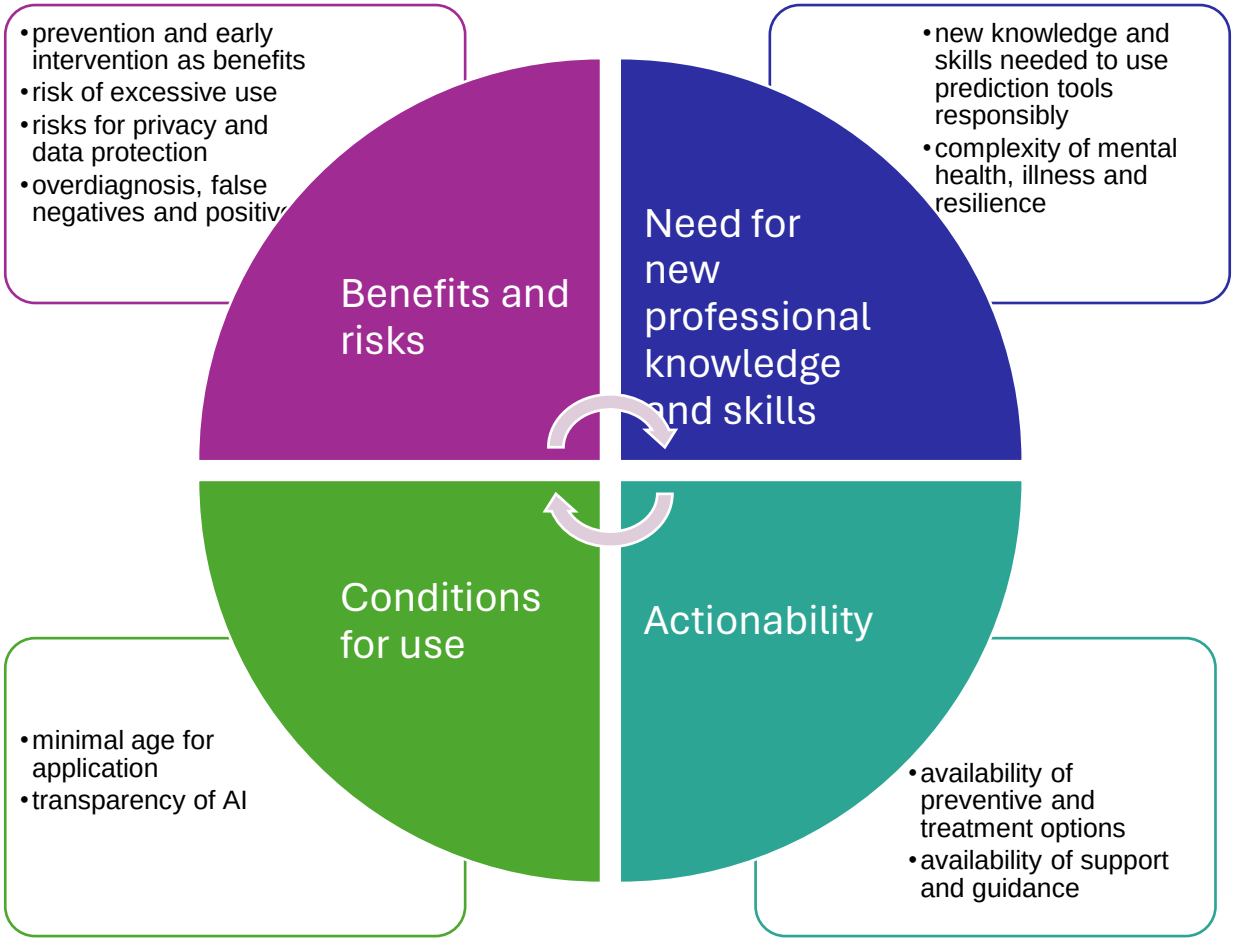

Figure 1. *The main themes and subthemes raised during the group discussions.*

Need for new professional knowledge and skills

When considering the future implementation of a novel predictive tool in clinical practice, participants emphasized the need to acquire professional knowledge about its background and skills to use the tool. Some of the examples of specific knowledge and skills mentioned during the group discussions included:

- ✓ understanding how the prediction model works;
- ✓ understanding how the predictive information can be used responsibly in clinical practice;
- ✓ skills to explain statistical information to lay people;
- ✓ understanding how to develop meaningful interpretations of the prediction model output;
- ✓ appreciation of the complexity of mental health, illness and resilience in a social and cultural context.

Knowledge transfer and adaptation from other fields of medicine, e.g. cardiovascular risk prevention, genetic counselling, or healthy lifestyle promotion were suggested as a way to move forward. In a broader context, participants also discussed the importance of professional skills for early detection of mental distress and trauma, and strengthening resilience, general communication skills and a need for professional guidelines for the use of prediction tools. Some participants mentioned that even a new healthcare profession might emerge, aimed at explaining mental illness risks and strengthening resilience.

Benefits and risks

The participants noted a positive future potential of predictive information in offering options for prevention, targeted interventions and counselling. Knowing the risks in general was viewed as a basis for early prevention and intervention. However, concerns about excessive, stigmatizing or even obligatory use of prediction tools were presented. Some of the questions asked about the potential application of prediction tools were:

- ✓ how should decisions to generate predictive information in a particular situation be made?
- ✓ who should participate in the decision-making?
- ✓ will results initially be available only for clinicians or will they be immediately shared with families?
- ✓ what information should be given to get informed consent?

Additionally, risks of overdiagnosis, false positive and false negative outcomes were noted as problematic for responsible future use. Some participants emphasized that it is important to realize that even in high-risk families, illness is not inevitable. The possible biases due to incomplete information or unwillingness of families to share all information necessary for prediction were also mentioned.

Actionability

Reflection on the actionability of predictive information led to further in-depth considerations and questions:

- ✓ are professionals, persons with mental illness and families able to make use of this information?
- ✓ will the predictive information be disclosed only in cases when there are opportunities for prevention or treatment?
- ✓ what does actionability mean in the context of prediction of mental illness?
- ✓ are there non-pharmacological prevention and treatment options available?

The availability of predictive information without appropriate counselling was a matter of concern. Participants also expressed concern that families may lack guidance and support for reasonable use of predictive information. Thus, it was suggested that families should be guided through the process at all stages: starting with informing about the availability of novel prediction tools; decision-making about use; collecting information necessary for prediction; interpretation of results and options for action.

Another challenge mentioned was related to the tool's ability to address individual risk of mental illness, bearing in mind that mental illness as a phenomenon is embedded in a broad context of more systemic problems, such as lack of mental health literacy, poverty, bullying etc.

Conditions for use

In addition to actionability, other conditions for the use of prediction tools were discussed, for example, the minimal age for the application of prediction tools. One of the perspectives included concerns about the potential misdiagnosis of psychopathology due to transient symptoms children and adolescents can show without actually developing mental illness later in life. This perspective points to the importance of avoiding stigmatization of individual symptoms. Another perspective highlighted that parents might become supersensitive and hypervigilant to any abnormality after receiving predictive information about risks, thus leading to restrictive and overprotecting parenting behavior. Some participants were concerned that risk prediction could initiate a self-fulfilling prophecy effect while others indicated that the risk for this is low.

Some risks mentioned during the discussions were related to the perception of the predictive tool as a "black box" with a potential to violate a person's autonomy and trust due to a lack of transparency. The participants mentioned that besides technical and legal trustworthiness, a tool also should be transparent regarding illness and resilience factors used in calculations, as well as provide information on which main factors contribute to the risk and resilience score of an individual. A group of questions was raised regarding privacy and data protection:

- ✓ who controls/owns the technology?
- ✓ who has access to the data and the predictive information?
- ✓ how will the privacy and safety of data be ensured?

It was emphasized that a clear legal framework is needed to protect the rights of persons and families, and transparency of AI might help to increase trust.

Conclusion

The 1st FAMILY Stakeholder Dialogue Event was a great success and provided valuable insights into participants' views on the ethical aspects and social consequences of prediction of risk of mental illness. The results of the discussion will be used in the process of development of the FAMILY survey on this same topic for healthcare professionals across Europe. We thank all the participants of the Stakeholder Dialogue Event for their time and contribution to the discussion.

Funded by the European Union, the Swiss State Secretariat for Education, Research and Innovation (SERI) and the UK Research and Innovation (UKRI) under the UK government's Horizon Europe funding guarantee' Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union, or the European Health and Digital Executive Agency (HADEA), the SERI or the UK Research and Innovation (UKRI). Neither the European Union nor the granting authorities can be held responsible for them.

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